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ABSTRACT

A review of research supported by the Department of Education's Office of Special Education Programs (OSEP) focuses on practical applications of research findings on family involvement in special education. The findings identify how family life can be utilized as a source of children's learning opportunities, concluding with four suggested procedures: a schedule for reminding parents to involve their children in learning activities; a matrix for focusing on the child's behaviors in different learning activities; parent responsiveness to desired child behavior as a teaching method; and family and community activities as learning opportunities on a child's Individualized Family Service Plan or Individualized Education Program. The findings also indicate that cultural reciprocity can aid collaboration with families with a recommended four-step recursive cultural reciprocity process. Other research indicates how families can be helped to deal with stress through early entry into the service system, provision of translators when needed, and access to information. The publication also summarizes the work of several OSEP supported organizations that specialize in providing support services and information to families of children with disabilities. These include the Parent Advocacy Coalition for Educational Rights (PACER) Center, the Federation of Families for Children's Mental Health (FFCMH), and the National Information Center for Children and Youth with Disabilities (NICHCY). (DB)

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IMPROVING FAMILY INVOLVEMENT
IN SPECIAL EDUCATION

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Improving Family Involvement in Special Education

THIS ISSUE:

FAMILY INVOLVEMENT



FOR OVER TWO DECADES, THE U.S. OFFICE OF SPECIAL EDUCATION PROGRAMS (OSEP) HAS SUPPORTED RESEARCH THAT CONSIDERS WAYS TO IMPROVE FAMILY INVOLVEMENT IN THE EDUCATION OF CHILDREN WITH DISABILITIES. THIS RESEARCH CONNECTIONS TAKES A LOOK AT CURRENT FINDINGS.

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Family involvement is considered essential to improving educational results for children with disabilities. As the *21st Report to Congress on the Implementation of Individuals with Disabilities Education Act* (IDEA) emphasized, family involvement is a strong factor affecting learning and school performance (U.S. Department of Education, 1999).

Family involvement in children's special education was an original tenet of IDEA, with family roles expanding with each reauthorization of the law. IDEA delineates several levels of parental rights in special education services for children from birth through age 21: consent, notification, participation in educational decisions about their children, and participation in policy making. The emphasis on parent involvement in the Part C program of IDEA for infants and toddlers is particularly strong, with its call for family-centered services to address the needs of the entire family

in relation to the child. Yet even with this long tradition of legislative support, parent involvement may not always reach desired levels, and in some cases may even be riddled with conflict.

According to family involvement consultant **Valerie Burrell-Muhammad**, unless service providers and families get beyond "entry level" compliance with IDEA requirements, the opportunity for true collaboration will be lost. "Parenting is a noble profession that must be honored," Burrell-Muhammad points out. "Mindsets must change to incorporate this belief—and that will take much education and training of both families and service providers."

How, then, can family involvement be improved? Recent lines of inquiry supported by OSEP have focused on this question. Several research-based approaches that show promise in increasing family involvement are presented in this *Research Connections*. ■

WHAT WE'VE LEARNED

Research Identifies Opportunities and Offers Solutions for Improving Family Involvement

With OSEP support, researchers are developing approaches that enhance families' abilities to contribute to their children's learning in the home and community. They also are identifying barriers to full family participation and suggesting solutions. Elements that can facilitate or limit family involvement are the types of activities families are expected to participate in, whether family members have sufficient preparation to feel comfortable participating, and school personnel's behavior toward family participation.

FAMILY LIFE AS A SOURCE OF CHILDREN'S LEARNING OPPORTUNITIES

"Our research has confirmed a basic fact: Parents do a very good job of engaging their children in a rich array of everyday learning experiences," **Carl Dunst**, researcher at the Orelena Hawks Puckett Institute in North Carolina tells us. "All settings have the potential to offer rich learning experiences—we just have to figure out what makes sense for a particular child and his or her family."

With OSEP support, Dunst and his colleagues have been studying how family and community life provides children different kinds of natural learning opportunities. "Family life provides a rich source of events that can be seized as learning opportunities," Dunst explains. "Parents can be partners in reinforcing school learning at home, especially if good communication has been established between the school and home and if goals in the Individualized Education Program (IEP) have been written to promote collaboration." A particular research focus has been on infants, toddlers, and preschoolers who have or are at risk for delays in their development—the goal



Researchers have identified activities that offer children opportunities to learn important life skills.

being to identify, develop, and evaluate ways of using family and community life as sources of learning activities and opportunities promoting child abilities.

Dunst conducted two national surveys of nearly 3,300 parents to learn about sources of children's learning activities and the kinds of practices associated with benefits to the child, parents, and family. Respondents were asked if the activities or settings listed on the survey were places where their children learned or exhibited desired behavior. Care was taken to ensure that activities listed made sense in terms of ethnic and cultural backgrounds of families across all walks of life.

"Findings from our research indicate that everyday family and community activity settings are real life, natural learning environments that make the most sense in terms of learning important life skills," Dunst explains (see the categories shown on page 3). "Consider these examples: a parent holding a baby on her lap while

pointing and talking about a robin sitting on a tree limb, dropping bread crumbs into a fish or duck pond and watching what ensues, asking a child to lift his arm while putting on a shirt—by participating in each of these activities, children learn about people and things in their world. When these activities enhance development, they foster a child's sense of mastery and knowing about his or her own capabilities." Findings show that children participate in many different social and physical settings—on average, children participate in some 150 different kinds of social and physical settings as part of family and community life.

Dunst has integrated his research findings into a model of early intervention that includes children's learning opportunities, parenting supports (e.g., information and guidance that strengthens existing parenting knowledge and skills), and family/community supports provided in a family-centered manner. As part of intervention studies with children

and their families, Dunst evaluated four procedures:

- A schedule for reminding parents to involve their children in learning activities.
- A matrix for focusing on the child's behaviors in different learning activities.
- Parent responsiveness to desired child behavior as a teaching method.
- Family and community activities as learning opportunities on a child's Individualized Family Service Plan (IFSP) or IEP.

"We found that participation in activities that matched and built upon children's interests was consistently associated with benefits to the child, parent, and family," Dunst reports. "We also discovered the KISS principle (keep it situational and simple), which has become a standard for guiding parent's capacity to include children with disabilities in participatory learning experiences."

Focusing on Child and Family Strengths

Michelle Davis provides direct service to families at the Puckett Institute in North Carolina. Davis says that everything must start and end with the child's and family's strengths. "I avoid using the word behavior or talking about problems the child may have," Davis explains. "Instead, I talk with families about what the child likes to do, what the child likes, and what makes the child smile."

The process is collaborative and recognizes family knowledge and expertise. "We generally start with sharing our views of the child's strengths," Davis explains. Families discuss the child's preferences and interests. Part of the conversation focuses on what an ordinary day in the family entails. Families start at the beginning of the day—what happens when the child

CATEGORIES OF FAMILY AND COMMUNITY ACTIVITY SETTINGS AND LEARNING OPPORTUNITIES

FAMILY LIFE

- Family Routines (e.g., cooking meals, food shopping)
- Parenting Routines (e.g., child's bedtime or bath time)
- Child Routines (e.g., dressing, grooming)
- Literacy Activities (e.g., storytelling, looking at books)
- Physical Play
- Play Activities
- Entertainment Activities (e.g., music, television)
- Family Rituals (e.g., family talks, saying grace)
- Family Celebrations (e.g., birthdays)
- Socialization Activities (e.g., visiting friends, family gatherings)
- Gardening Activities

COMMUNITY LIFE

- Family Excursions (e.g., car or bus rides)
- Family Outings (e.g., visiting friends, eating out)
- Play Activities
- Community Events (e.g., going to the library)
- Outdoor Activities (e.g., parades, walks)
- Recreation Activities (e.g., swimming)
- Children's Attractions (e.g., museums, zoo)
- Art/Entertainment Activities
- Church/Religious Groups
- Organization/Groups (e.g., classes)
- Sports Activities/Events

wakes up, gets dressed, and eats breakfast—and continue to the end of the day. The focus always is on opportunities for the child to be involved with the family.

"Typically, we discuss things that the child likes to do with other family members," Davis says. "From there we spend time discussing how those activities might be enhanced. For example, a parent might identify meal time as something the child loves. Upon further discussion, it becomes

apparent that the family usually is talkative during the meal. "So, we might decide to enhance the child's language production during the mealtime."

Davis says that the process of suggesting responsive techniques (e.g., enhancing the child's language production) is collaborative. "The emphasis is always on engaging the child in the interaction with the parent responding to the child," Davis adds. Davis stresses that it is important to enhance naturally occurring activities, rather than add extra things for the family to do. "The goal is to find ways to build on what the family is already contributing to their child's learning and growth."

CULTURAL RECIPROCITY AIDSL COLLABORATION WITH FAMILIES

A service provider and family member meet for the first time. If the parent's perspective of the world is similar to the service provider's, then a positive connection generally occurs. However, if the parent holds a belief system different than the service provider's, difficulties typically arise. According to University of Miami researcher, Beth Harry, the source of the difficulty often is a point of view that is defined and limited by cultural orientation. Helping families and service providers find mutual ground for communication served as the focus for the OSEP-funded Longitudinal Family Study, conducted by Harry and her colleague Monimalka Day. The study was part of a larger initiative of the Consortium for Collaborative Research on Social Relationships.

According to Harry, stumbling blocks often arise when service providers and families do not recognize and accept the other culture. Harry cites the following illustration: "A service provider may view disability as a physical phenomenon, as something that can be measured and treated in a scientific way. This will conflict

continued on page 4

Research Identifies Opportunities (continued)

with a parent who may, as a result of cultural background, view disability as a blessing or a punishment, that is to be treated by spiritual means. Unless the service provider recognizes his or her own assumptions in the context of this interchange, he or she may judge the parent as irrational."

Harry contends that culture influences our assumptions about disability. "For example, in another study I found that individuals from Puerto Rican backgrounds tended to view disabilities as more severe conditions than do people from the mainstream United States—in fact, many of our high incidence disabilities were not seen by them as disabilities, but simply as individual characteristics within the normal range," Harry explains. "We observed that when parents from Puerto Rico realized their views were not valued by Anglo service providers, they stopped participating in their child's educational process."

As the U.S. becomes more diverse, different cultural beliefs and practices are more often cited as a barrier to effective interaction. However, many researchers have noted that it is most often people from the minority group who are required to understand or become acculturated to the ways of the majority group. "The process of acculturation takes time, and professionals who are hoping to make a difference for children must be willing to take the initiative in building a bridge between the cultures of diverse families and the culture of schools," Harry asserts. To do this, Harry advocates that professionals initiate a two-way process of information sharing and understanding called cultural reciprocity.

The cultural reciprocity process is recursive, meaning that each step informs the others. The steps are

Step 1: Identify the cultural values that are embedded in your interpretation of a

student's difficulties or in the recommendation for service. For example, imagine that you have recommended that a young adult with developmental disabilities move out of the family home into a small group home or supported apartment. Ask yourself which values underlie your recommendation. For many of us, central to our recommendation will be the values of equity, independence, and individuality. Next, analyze your experiences that contributed to your holding these values. Consider the roles of nationality, culture, socio-economic status, and professional education in shaping your values.

"Working with families in the U.S. means working with multicultural families. There should be a strong multicultural and family component in every teacher education program."

Beth Harry, Researcher, University of Miami

Step 2: Find out whether the family being served recognizes and values your assumptions, and if not, how their view differs from yours.

Step 3: Acknowledge and give explicit respect to any cultural differences identified, and fully explain the cultural basis of your assumptions.

Step 4: Through discussion and collaboration, set about determining the most effective way of adapting your professional interpretations or recommendations to the value system of this family.

"By developing your own cultural self-awareness, you are able to recognize the cultural underpinnings of your professional practice," Harry points out. "This, in turn,

enables you to facilitate conversations with the families with whom you interact, toward identifying the values and beliefs that underlie their priorities, goals, and vision for their child." Harry adds that through the process, families also acquire knowledge about the special education system, which supports them in making informed decisions about services. "With cultural reciprocity, we find not only better relationships, but more reasonable goals that are implemented."

Building Reciprocity—A Personal Account

"Before learning the reciprocity process, I was somewhat closed minded," Yamile Llano, who is Hispanic of Cuban origin and teaches at Felix Varela Senior High School in Miami, FL, shares. "But now I understand that where there is love, there is acceptance."

As a graduate student in one of Harry's special education courses, Llano was required to participate in a number of activities with families based on Harry's cultural reciprocity research. One activity involved attending a social event with one of her students and his or her family. Llano selected Jack, an African American youngster, and arranged to attend church with him and his family. Following is an excerpt from Llano's journal entry.

"...I was very nervous. I was on my way to a Baptist church in a predominantly black neighborhood. My stomach was in knots...I am of Catholic faith and I was not sure what to expect. As I waited for the family, many people looked at me as if I were lost. I really did not fit in, I stood out like a sore thumb...I felt as if I were intruding. As people stared at me, I simply smiled and said 'Hello'. I just wanted to disappear. When I saw Jack's family, I felt more comfortable. They welcomed me very warmly and Jack shook my hand for the

first time. It was then I felt I was in a very warm atmosphere. The church felt like one big family—very different from the church I regularly attend. At my church, when people walk in, they are very quiet and very careful not to make the slightest noise. At Jack's church, everyone was happy and no one whispered. This made me feel good. Jack's family interacted with everyone. I noticed that everyone greeted Jack—just like everyone else. No one treated him differently. Jack was accepted as he was. I tried to see if anyone treated Jack differently, but I saw no evidence of that. Instead, what I saw was a close knit community that was accepting of Jack's disability."

According to Llano, that experience taught her a lot about herself. "Many times we make assumptions about people based on race, religion, and other factors that hinder us into not mixing and mingling with other people. I thought people in the church would not be accepting of me because of my race and my religion—but I was wrong!" Llano encourages other service providers to move outside their circles and experience, as she did, into her students' families and lives. "You will feel richer for the experience."

HELPING FAMILIES DEAL WITH STRESS

For almost two decades, researcher **George Singer** at the University of California-Santa Barbara has been studying the effects of parenting a child with a disability with an eye toward how service providers may better support children with disabilities and their families. In recent years, Singer has turned his attention to the experience of new immigrants upon learning that their child is disabled.

"Families for whom English is not spoken as the first language often face increased stress," Singer says. In one study, Singer investigated Latino families in the neonatal intensive care unit (NICU) of a

hospital. "The NICU is the point of entry into the service system for children with disabilities, as infants with very low birth weight are at high risk for developmental disabilities," Singer explains. "An encounter with the NICU normally generates high levels of stress, and for some, clinical levels of depression and anxiety for English speaking people in the majority culture. We suspected that such stress would be magnified among Latino, limited English proficiency families."

As suspected, results indicated that in addition to basic levels of stress associated with the NICU experience, the Latino families in the study experienced an added level of stress due to communication and cultural barriers. "In all cases, there was a real need for information. The communication/cultural barriers often led to misunderstandings, distrust, and a perceived inaccessibility of doctors and nurses," Singer noted. "Any attempts at communication, however, were perceived by the families as beneficial." The families

in Singer's research identified several coping mechanisms: support from extended family members, parent-to-parent contact, involvement of the infant's siblings, and religion/faith.

In another study, Singer and his colleagues investigated the experiences of Korean immigrants and found that while Korean families tend to cope with parenting a child with a severe disability (e.g., autism, Down syndrome), the ongoing challenges of raising the child may be stressful. "Overall, for Korean families the challenges include difficulties in access to social services and communication difficulties with professionals due to language barriers," Singer reports. "These families particularly need support immediately after diagnosis when many reported a severe emotional crisis."

According to Singer, providing translators is essential. Also, parents need access to information. "Often children are not served because their parents are not aware of available services, of what is possible," Singer adds. ■

RESOURCE

PEER PROJECT: FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

"Parent participation has changed over time—it has evolved from pioneering efforts to ensure that a child with disabilities gained access to services to making an impact on systems," says **Richard Robison**, Executive Director of the Federation for Children with Special Needs (FCSN). FCSN directs the OSEP-funded Parents Engaged in Education Reform (PEER) project. PEER believes that all children should be included in standards-based education reform and its accountability systems.

As part of the PEER project, Director **Carolyn Romano** and her colleagues developed the manual, *Every Single Student: A PEER Resource Manual on Standards-based Education and Students with Disabilities* (download from www.fcsn.org/peer) which provides families with information about how they might participate in education reform efforts. Sections

cover topics such as standards, accommodations, assessment, transition, curriculum and instruction, IDEA, and the legal basis for including children with disabilities in education reform. Each includes an information brief and a shorter fact sheet which can be disseminated widely. "We wanted to make sure that parents and parent leaders understood education reform so that they could ensure that children with disabilities received the benefits of reform," Romano explained. Among the many benefits of including children with disabilities in reform, Romano cites the following:

- Higher standards and expectations for all.
- Access to the general education curriculum.
- Accountability for schools and students.
- More parents of children with disabilities involved in the regular education system.

VIEWS FROM THE FIELD

A Look at National Organizations Supporting Families

OSEP supports a number of organizations that specialize in providing support, services, and information to families of children with disabilities. The goal is to better prepare families to participate in their children's education.

PACER CENTER: PROVIDING SUPPORT FOR FAMILIES TO PARTICIPATE IN ALL PHASES OF THEIR CHILD'S EDUCATION

"In schools where family involvement is valued, you will find more trust and fewer disagreements," says **Sue Abderholden**, Associate Director of the Parent Advocacy Coalition for Educational Rights Center (PACER). Abderholden stresses that family involvement is not always easy due to misconceptions and lack of understanding. "School personnel need to understand that parents will fight for their child's success and happiness. Families want the best for their children, but they may not always know how to get it."

"To be full partners with school personnel in implementing IDEA, parents must have information," **Paula Goldberg**, Executive Director, reports. "And parents should be involved in planning, developing, and disseminating that information."

Founded in 1977, the PACER Center, which is supported in part by OSEP, is a parent training organization that is based on the concept of parents helping parents. "PACER was created by parents of children with disabilities to help other families facing similar challenges," Goldberg says. Today, the PACER staff, which consists primarily of parents, provides a variety of services including parent training, publications, and technical assistance on topics such as

- General special education information.
- Early childhood intervention.
- Multicultural services, including language and cultural issues faced by culturally and racially diverse parents of children with disabilities.
- Transition to adult life.
- Juvenile justice and identifying the needs of youth with disabilities in that system.

Many of the publications—available on the PACER web site at www.pacer.org—are available in Spanish and Hmong, as well as English.

In addition to being a parent information center itself, PACER also directs the OSEP-funded Technical Assistance Alliance for Parent Centers (the Alliance) which provides technical assistance to the 90 federally funded Parent Training and Information Centers (PTIs) and Community Parent Resource Centers in each state. "These centers provide training and information to parents of infants, toddlers, children, and youth with disabilities and to professionals who work with children," Abderholden explains. "This assistance helps parents participate more effectively with professionals in meeting the educational needs of children with disabilities." [The toll-free number for the Alliance project is 888-248-0822 and the web site is www.taalliance.org.]

PACER was recently awarded one of the OSEP IDEA Partnership Projects. Called FAPE (Families and Advocates Partnership for Education), the project links with other parent training information centers and national organizations to inform families and advocates about IDEA. Visit the FAPE website at www.fape.org.

FFCMH: INVOLVING FAMILIES IN SYSTEMS CHANGE

During the past decade, many child service systems have evolved from being family focused to being family driven. Rather than treating families as the object of an intervention, the emphasis now is on building a collaborative working environment where families are respected as the change engine driving both system reforms and better outcomes for individual children.

"Family involvement for systems change means actively reaching out to engage, train, and support family members representative of the children enrolled in or served by a system, agency, school, or program so that their experiences and perspectives collectively drive policy and service planning, implementation, and evaluation," explains **Trina Osher**, Coordinator of Policy and Research at the Federation of Families for Children's Mental Health, a national family-run organization focused on the needs of children and youth with emotional, behavioral, or mental disorders and their families. "With appropriate training, family members and family-run organizations are increasingly partnering with formally trained personnel in school and community settings to run service programs and systems."

According to Osher, true family involvement has several key features:

- Family involvement is a collective effort requiring representation from all cultural, ethnic, and racial groups in the community in numbers sufficient to allow each a real voice, with no one voice dominating.

- Family involvement requires that systems, agencies, schools, and programs provide family members with information necessary to participate in discussions and the tools to understand this information and make decisions (for example, they are given opportunities to learn how to read and interpret a wide range of reports, budgets, charts, and policy options that document what is going on, what is working well, and what needs to be changed; they are provided with essential information prior to a discussion).
- Families must receive fair compensation for their time and for the expenses incurred in being involved (for example, stipends to replace lost wages or sacrificed vacation time, pre-paid transportation, and child care).
- Families must have respect and recognition from administrators and service providers with whom they partner. Developing this respect is a mutual responsibility. System personnel need to replace stereotypical images of families as being "dysfunctional" with realistic appraisals of their strengths, skills, talents, and the contributions families can make to system improvements. Family members, in turn, need to transform their negative experiences into constructive dialogue with system personnel to define solutions to address these issues.
- Families and system personnel must learn how to share both the power and responsibility for making decisions together.
- Families need training and technical assistance to develop the skills necessary for leadership and partnership for system change. Specific training needs must be identified by families, and training programs, materials, and activities should be tailored to their learning and cultural preferences. While training should be driven by families, experts

and authorities from related fields should collaborate in curriculum development.

To support families in carrying out the roles and responsibilities associated with this new approach to family involvement, the Federation of Families for Children's Mental Health provides training that enables family members to participate effectively as leaders in research and evaluation, staff development, and technical assistance. One of the Federation's programs, the *World of Evaluation: How to Make It Yours*, offers training to family members in how to use and participate in evaluation and research for advocacy purposes. "The course was developed in response to needs identified by families of children who have emotional and behavioral disorders who wanted to know how they could tell when the results of research on children's mental health were reliable and applicable to their own children or children in their community," Osher points out.

NICHCY: ACCESSING INFORMATION WHEN IT IS NEEDED

"The need for information is ongoing for families," reports **Suzanne Ripley**, Director of the National Information Center for Children and Youth with Disabilities (NICHCY). "All families want their children to be successful and happy in school. They call NICHCY to find out more about educational opportunities and how to get their children the services they need." While the type of information families need for infants and toddlers may be quite different than that for a child who is transitioning to adult life, Ripley asserts that in all cases parents need current and accurate information that is based on research and best practice.

Funded by OSEP, NICHCY is charged with providing families with information to make informed decisions about their child's education. However, NICHCY also serves administrators, teachers, and

related service providers. Ripley notes, "It's interesting that these different groups have similar questions—the most common being 'How do I provide for the needs of a particular child.'" The three disability areas about which users have the most questions are autism, learning disabilities, and Attention Deficit Hyperactivity Disorder. "We also see a lot of interest in secondary schools and elementary schools, but receive fewer inquiries about the middle years."

In addition to collecting and sharing information, NICHCY answers questions, links people with others who share common concerns, publishes information, and maintains a data base of referral resources. "An advantage of NICHCY products is that they are written in a consumable, usable format," Ripley says. "One of our goals is to translate research into practice." NICHCY's resources can be downloaded directly from its web site (www.nichcy.org), which last year logged more than one million visitors. Many of the NICHCY products are available in Spanish and alternate formats. ■

RESOURCE

DIVISION FOR EARLY CHILDHOOD

"Family involvement is essential to providing effective services to infants, toddlers, and young children with special needs," says **Barbara Smith**, executive director of the Division for Early Childhood (DEC) of the Council for Exceptional Children. DEC is a professional membership organization concerned with early childhood special education. "Providing services to the child and his or her family in addition to family involvement cuts across DEC's position statements and resolutions." Examples include:

- *Position on Inclusion*
- *Position on Services for Children Birth to Age Eight with Special Needs and their Families*

Find these publications and other useful information on the DEC web site at: www.dec-sped.org. DEC is at 1380 Lawrence Street, Suite 650, Denver, CO 80204.

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RESOURCE

FEDERAL INTERAGENCY COORDINATING COUNCIL

The FICC web site at www.fed-icc.org provides information for parents to help ensure that services for young children who are served under IDEA are of the highest quality. A founding precept of the FICC is involving family members at all levels of policy and service delivery planning, development, implementation, and evaluation.

RESEARCH CONNECTIONS is a biannual review of research on topics in special education, focusing on research sponsored by the U.S. Office of Special Education Programs.

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